
The Values Underlying Informed Consent

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What are the values that ought to guide decisionmaking in the provider-patient relationship or by which the success of a particular interaction can be judged? The Commission finds two to be central: promotion of a patient's well-being and respect for a patient's self-determination.¹ Before turning to the components of informed consent (Part Two of this Report) or the means for promoting its achievement (Part Three), these central values will be explored. They are in many ways compatible, but their potential for conflict in actual practice must be recognized.²

¹ Although these principles have been discussed in judicial decisions and legal commentary on informed consent, the concern of the Commission with patient-provider communication and with decisionmaking in health care in general causes it to consider the issue in a way that is broader and more complex than the legal doctrine. The implications of this discussion for law are noted at appropriate points, however, and conclusions about those implications are given in Part Three.

² Pursuit of these two values is constrained in various ways, most notably by society's overall interest in equity, justice, and maximum social welfare. These issues are the central concerns of the Commission's forthcoming report *SECURING ACCESS TO HEALTH CARE*. Because these goals need not be central to the decisionmaking process of patients and providers, this report does not take up the complications arising from conflicts between legitimate societal goals and individual patient goals. The Commission's forthcoming report on decisions about life-sustaining therapy explores the relationship between societal and individual concerns in the context of a particular set of health care decisions.

Serving the Patient's Well-Being

Therapeutic interventions are intended first and foremost to improve a patient's health. In most circumstances, people agree in a general way on what "improved health" means. Restoration of normal functioning (such as the repair of a fractured limb) and avoidance of untimely death (such as might occur without the use of antibiotics to control life-threatening infections in otherwise healthy persons) are obvious examples. Health care is, in turn, usually a means of promoting patients' well-being. The connection between a particular health care decision and an individual's well-being is not perfect, however. First, the definition of health can be quite controversial: does wrinkled skin or uncommonly short stature constitute impaired health, such that surgical repair or growth hormone is appropriate? Even more substantial variation can be found in ranking the importance of health with other goals in an individual's life. For some, health is a paramount value; for others—citizens who volunteer in time of war, nurses who care for patients with contagious diseases, hang-glider enthusiasts who risk life and limb—a different goal sometimes has primacy.

Absence of Objective Medical Criteria. Even the most mundane case—in which there is little if any disagreement that some intervention will promote health—may well have no objective medical criteria that specify a single best way to achieve the goal. A fractured limb can be repaired in a number of ways; a life-threatening infection can be treated with a variety of antibiotics; mild diabetes is subject to control by diet, by injectable natural insulin, or by oral synthetic insulin substitutes. Health care professionals often reflect their own value preferences when they favor one alternative over another; many are matters of choice, dictated neither by biomedical principles or data nor by a single, agreed-upon professional standard.

In the Commission's survey it was clear that professionals recognize this fact: physicians maintained that decisional authority between them and their patients should depend on the nature of the decision at hand. Thus, for example, whether a pregnant woman over 35 should have amniocentesis was viewed as largely a patient's decision, whereas the decision of which antibiotic to use for strep throat was seen as primarily up to the doctor. Furthermore, on the question of whether to continue aggressive treatment for a cancer patient with metastases in whom such treatment had already failed, two-thirds of the physicians felt it was not a scientific, medical decision, but one that turned principally on personal values. And the same proportion felt the decision should be made jointly (which 64% of the doctors claimed it usually was).

Patient's Reasonable Subjective Preferences. Determining what constitutes health and how it is best promoted also requires knowledge of patients' subjective preferences. In pursuit of the other goals and interests besides health that society deems legitimate, patients may prefer one type of medical intervention to another, may opt for no treatment at all, or may even request some treatment when a practitioner would prefer to follow a more conservative course that involved, at least for the moment, no medical intervention. For example, a slipped disc may be treated surgically or with medications and bed rest. Which treatment is better can be unclear, even to a physician. A patient may prefer surgery because, despite its greater risks, in the past that individual has spent considerable time in bed and become demoralized and depressed. A person with an injured knee, when told that surgery has about a 30% chance of reducing pain but almost no chance of eliminating it entirely, may prefer to leave the condition untreated. And a baseball pitcher with persistent inflammation of the elbow may prefer to take cortisone on a continuing basis even though the doctor suggests that a new position on the team would eliminate the inflammation permanently. In each case the goals and interests of particular patients incline them in different directions not only as to how, but even as to whether, treatment should proceed.

Given these two considerations—the frequent absence of objective medical criteria and the legitimate subjective preferences of patients—ascertaining whether a health care intervention will, if successful, promote a patient's well-being is a matter of individual judgment. Societies that respect personal freedom usually reach such decisions by leaving the judgment to the person involved.

The Boundaries of Health Care. This does not mean, however, that well-being and self-determination are really just two terms for the same value. For example, when an individual (such as a newborn baby) is unable to express a choice, the value that guides health care decisionmaking is the promotion of well-being—not necessarily an easy task but also certainly not merely a disguised form of self-determination.

Moreover, the promotion of well-being is an important value even in decisions about patients who can speak for themselves because the boundaries of the interventions that health professionals present for consideration are set by the concept of well-being. Through societal expectations and the traditions of the professions, health care providers are committed to helping patients and to avoiding harm. Thus, the well-being principle circumscribes the range of alternatives offered to patients: informed consent does not mean that patients can insist upon anything they might want. Rather, it is a choice among medically accepted and available options, all of which

are believed to have some possibility of promoting the patient's welfare, including always the option of no further medical interventions, even when that would not be viewed as preferable by the health care providers.

In sum, promotion of patient well-being provides the primary warrant for health care. But, as indicated, well-being is not a concrete concept that has a single definition or that is solely within the competency of health care providers to define. Shared decisionmaking requires that a practitioner seek not only to understand each patient's needs and develop reasonable alternatives to meet those needs but also to present the alternatives in a way that enables patients to choose one they prefer. To participate in this process, patients must engage in a dialogue with the practitioner and make their views on well-being clear. The majority of physicians (56%) and the public (64%) surveyed by the Commission felt that increasing the patient's role in medical decisionmaking would improve the quality of health care.³

Since well-being can be defined only within each individual's experience, it is in most circumstances congruent to self-determination, to which the Report now turns.

Respecting Self - Determination

Self-determination (sometimes termed "autonomy") is an individual's exercise of the capacity to form, revise, and pursue personal plans for life.⁴ Although it clearly has a much broader application, the relevance of self-determination in health care decisions seems undeniable. A basic reason to honor an individual's choices about health care has already emerged in this Report: under most circumstances the outcome that will best promote the person's well-being rests on a subjective judgment about the individual. This can be termed the instrumental value of self-determination.

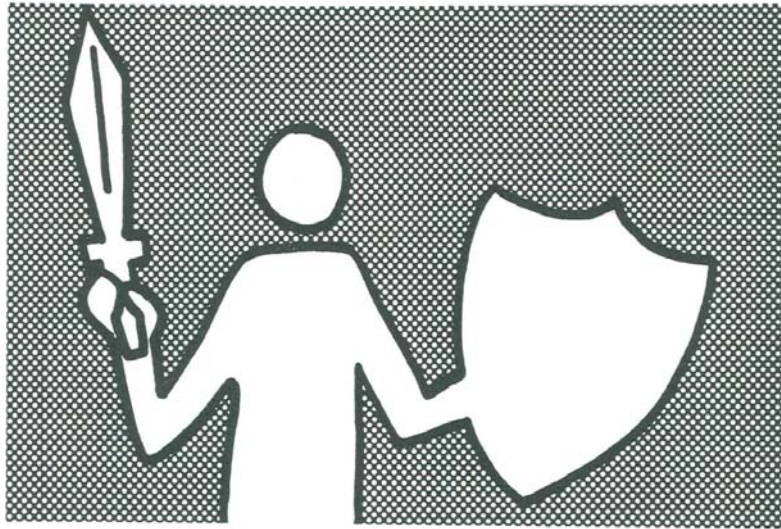
More is involved in respect for self-determination than just the belief that each person knows what's best for him- or herself, however. Even if it could be shown that an expert (or a computer) could do the job better, the worth of the individual, as acknowledged in Western ethical traditions and especially

³ Many physicians and patients said they believed an increased patient role would give the patient a better understanding of the medical condition and treatment, would improve physician performance in terms of the honesty and scope of discussion, and would generally improve the doctor-patient relationship. However, a number of physicians claimed that greater patient involvement would improve the quality of care because it would improve compliance and would make patients more cooperative and willing to accept the doctor's judgment.

⁴ Gerald Dworkin, *Autonomy and Informed Consent* (1982), Appendix G, Volume Three of this Report, at section 5.

in Anglo-American law, provides an independent—and more important—ground for recognizing self-determination as a basic principle in human relations, particularly when matters as important as those raised by health care are at stake. This noninstrumental aspect can be termed the intrinsic value of self-determination.

Intrinsic Value of Self-Determination. The value of self-determination readily emerges if one considers what is lost in its absence. If a physician selects a treatment alternative that satisfies a patient's individual values and goals rather than allowing the patient to choose, the absence of self-determination has not interfered with the promotion of the patient's well-being. But unless the patient has requested this course of conduct, the individual will not have been shown proper respect as a person nor provided with adequate protection against arbitrary, albeit often well-meaning, domination by others. Self-determination can thus be seen as both a shield and a sword.



Freedom from interference. Self-determination as a shield is valued for the freedom from outside control it is intended to provide. It manifests the wish to be an instrument of one's own and "not of other men's acts of will."⁵ In the context of health care, self-determination overrides practitioner-determination even if providers were able to demonstrate that they could (generally or in a specific instance) accurately assess the treatment an informed patient would choose. To permit action on the basis of a professional's assessment rather than on a patient's choice would deprive the patient of the freedom not to be forced to do something—whether or not that person would

⁵ Isaiah Berlin, *Two Concepts of Liberty*, in *FOUR ESSAYS ON LIBERTY*, Clarendon Press, Oxford (1969) at 118-38.

agree with the choice. Moreover, denying self-determination in this way risks generating the frustration people feel when their desires are ignored or countermanded.

The potential for dissatisfaction in this regard is great. In the Commission's survey, 72% of the public said that they would prefer to make decisions jointly with their physicians after treatment alternatives have been explained. In contrast, 88% of the physicians believe that patients want doctors to choose for them the best alternative. Despite these differences in perception, only 7% of the public reports dissatisfaction with their doctors' respect for their treatment preferences.⁶

Creative self-agency. As a sword, self-determination manifests the value that Western culture places on each person having the freedom to be a creator—"a subject, not an object."⁷ Within the broad framework of personal characteristics fixed during the years of development, individuals define their own particular values.⁸ In these ways, individuals are capable of creating their own character and of taking responsibility for the kind of person they are. Respect for self-determination thus promotes personal integration within a chosen life-style.

This is an especially important goal to be nourished regarding health care. If it is not fostered regarding such personal matters, it may not arise generally regarding public matters. The sense of personal responsibility for decisionmaking is one of the wellsprings of a democracy. Similarly, when people feel little real power over their lives—in the economy, in political affairs, or even in their daily interactions with other people and institutions—it is not surprising that they are passive in encounters with health care professionals.

If people have been able to form their own values and goals, are free from manipulation, and are aware of information relevant to the decision at hand, the final aspect of self-determination is simply the awareness that the choice is their own to make. Although the reasons for a choice cannot always be defined, decisions are still autonomous if they reflect someone's own purposes rather than external causes unrelated to the person's "self." Consequently, the Commission's concept

⁶ This finding should be viewed cautiously since it is well known that surveys overstate the extent of actual satisfaction, as measured during on-site interviews immediately following doctor-patient encounters.

⁷ Berlin, *supra* note 5.

⁸ This is not to deny, of course, people's interdependence nor the ways in which each person's values are influenced by others. But people either incorporate or reject such influences into their own conception of what is good. In this view, self-determination lies in the relation between people's values and their actual desires and actions. An individual is self-determined or autonomous when that person is the kind of person he or she wants to be. Self-determination does not imply free will in the sense of a will free of causal determination.

of health care decisionmaking includes informing patients of alternative courses of treatment and of the reasoning behind all recommendations. Self-determination involves more than choice; it also requires knowledge.

The importance of information to self-determination emerged in the Commission's study of treatment refusals in hospitals. There it was found that, regarding routine treatments, information was frequently so lacking that patient self-determination was compromised.

Often patients were not told what treatment or procedure had been ordered for them, much less asked to decide whether or not to accept it. The purpose of the procedure was frequently obscure and the risks commonly went unmentioned. Presentation of alternatives was extraordinarily rare. The main concern of the patients we interviewed was not to select the best treatment from those available, but to find out what was being selected for them and why.⁹

Implications of Self-Determination. Despite the importance of self-determination, its exercise is sometimes impermissible and at other times impossible. That is, society sometimes must impose restrictions on the range of acceptable patient choices; at other times, patients either cannot, or at least do not, exercise self-determination.

External limitations. Two restrictions are recognized on the range of patient decisions that should be respected. First, some objectives are so contrary to the public interest or the interests of others that society bars the use of medical interventions toward these ends. For example, physicians may

⁹ Paul S. Appelbaum and Loren H. Roth, *Treatment Refusal In Medical Hospitals* (1982), Appendix D, in Volume Two of this Report. Although this lack of information and resulting patient noninvolvement in decisionmaking seems to have been a cause of treatment refusal they also occurred in many cases in which patients did not refuse treatment. Nonprovision of relevant information was also observed in the other on-site study.

One caveat must be noted, however. The Appelbaum-Roth team observed house-staff/patient interactions extensively but generally did not have a chance to observe interactions between attending physicians and patients. One would expect that discussions of major treatments and procedures, especially major surgical procedures, which were more often left to the attendings, might correspond more closely to the doctrine of informed consent. However, the investigators' conclusions are probably valid for the discussions about diagnostic procedures, medications, and adjunctive therapies as discussed in the other observational study conducted for the Commission. See Charles W. Lidz and Alan Meisel, *Informed Consent and the Structure of Medical Care* (1982), Appendix C, in Volume Two of this Report.

not assist patients in criminal activity (such as defacing fingertips so they will not leave identifiable fingerprints). The professional norms or moral integrity of health care professionals (individually, or collectively in health care institutions) may also conflict with the desires of a patient. When this occurs, the practitioner must first reexamine his or her own beliefs and preconceptions. If the proposed intervention would actually compromise the provider's integrity or standards, the patient will either have to accept the limitation on available interventions or seek another health care provider. Finally, a particular treatment preferred by a patient occasionally calls on very scarce resources that society (or some legitimate resource-controlling segment of the health care system) has decided to allocate to another use. Even as a "sword," self-determination does not invest a patient with rights to demand use of resources that have legitimately been allocated to others—as in the case, for example, of a patient who cannot have elective surgery on a desired date because all beds in a hospital are being used by disaster victims.

A second limitation on self-determination arises when a person's decisionmaking is so defective or mistaken that the decision fails to promote the person's own values or goals. This can happen in many ways: someone could fail to understand relevant information, such as the risks of a particular treatment, or unconsciously distort unpleasant information, such as the frightening diagnosis of cancer, and so forth. For example, a man in the prime of a full and rewarding life who has great plans for the future suddenly suffers a myocardial infarction in the middle of a poker game in which he has already won handsomely. Yet he refuses to permit himself to be transported to a hospital because he wants to play out his hand. The quality of his decisionmaking capacity is certainly in doubt. If his expressed wishes are respected nonetheless, the results in terms of self-determination would be mixed. Self-determination would be promoted in the sense that he has made the decision for himself, as opposed to having someone else make it, but self-determination would be contravened in that the decision is not the one that would best advance the man's apparent wish to live a long, full life.

Self-determination is valuable in both its roles—in letting an individual be his or her own decisionmaker and in securing each person's own goals. In situations where there is a choice of respecting the individual's decision or overriding it—that is, of favoring one aspect of self-determination at the expense of the other—overriding an individual decision is usually justified on the ground of promotion of well-being rather than of respect for self-choice.¹⁰

¹⁰ Likewise, self-determination is not an adequate guiding principle regarding decisions for persons who suffer permanent or chronic

The absence of contemporaneous choice. Sometimes people anticipate that they will be unable to participate in future decisions about their own health care. A patient, for example, may be under anesthesia during surgery at a time when diagnostic tests force a decision about a further operation. Similarly, patients with an early diagnosis of senile dementia of the Alzheimer's type can expect that their physical functioning might continue long after they are mentally incapable of deciding about care. Through an "advance directive" such people can specify the types of care they want (or do not want) to receive or the person they want to make such decisions if they are unable to do so.¹¹ Honoring such a directive shows respect for self-determination in that it fulfills two of its three underlying values.

First, following a directive, particularly one that gives specific instructions about types of acceptable and unacceptable interventions, fulfills the instrumental role of self-determination by providing reassurance that a course of conduct promotes the patient's subjective, individual evaluation of well-being. Second, honoring the directive shows respect for the patient as a person. To disregard it would be nearly as great an insult as to disregard the wishes of a patient who expresses them at that time.

An advance directive does not, however, provide self-determination in the sense of active moral agency by the patient on his or her own behalf.¹² Although any discussion between patient and health care professional leading up to a directive would involve active participation and shared decisionmaking, that would have been in the past by the time the decision actually needs to be made about the patient's health care. At that point, there is no "self," in the active, mental sense, to determine what should be done.

mental impairment, such as those who are severely mentally retarded or demented, who are incapable of forming a set of values or of applying them in particular decisions. The decisions for these patients rest instead on an assessment of what would promote their "best interests" (*i.e.*, well-being); *see* pp. 178-80 *infra*.

For an interesting example of some of the difficulties that may exist in determining whether an individual's choice reflects his or her long-term goals and values, *see* Albert R. Jonsen, Mark Siegler, and William J. Winslade, *CLINICAL ETHICS*, Macmillan Publishing Co., New York (1982) at 78-81.

¹¹ In the Commission's survey, 36% of the public reported that they have given instructions to someone about how they would like to be treated if they become too sick to make decisions, although only 23% of those instructions are in writing.

¹² *See generally* Paul Ramsey, *THE PATIENT AS PERSON*, Yale University Press, New Haven (1970).

Consequently, self-determination is involved when a patient establishes a way to project his or her wishes into a time of anticipated incapacity. Yet it is a sense of self-determination lacking in one important attribute: active, contemporaneous personal choice. Hence a decision not to follow an advance directive may sometimes be justified even when it would not be ethical to disregard a competent patient's contemporaneous choice.¹³

Active participation. Because patient noninvolvement in treatment decisions occurs frequently in medical care,¹⁴ it is important to understand whether it is compatible with patient self-determination. First and foremost, patients must be aware that they are entitled to make a decision about treatment rather than merely acquiescing in a professional's recommendation. Some patients feel, for example, that making a particular treatment decision will cause them great distress, or that the complexity and uncertainty of certain decisions make them poor decisionmakers and that trusted physicians or family members would be more likely to choose the treatment most in accord with the patients' own goals and values. Alternatively, some patients simply wish others to decide so that they can spend their time and energy on other matters. This, too, could constitute a transfer of the right to decide.

In contrast, some patients defer to physicians because they believe they have no business interfering in the exercise of medical judgment. Such patients do not think they are transferring their "right to decide" to a physician because they do not in the first place believe they have any right to decide about medical treatment. This is not an exercise of self-determination. Rather, self-determination occurs when patients understand decisions are theirs to make—and also to countermand if they are dissatisfied.¹⁵ In other words, self-determination requires that patients either make a choice or actually give the decisionmaking authority to another, not merely fail to act out of fear or ignorance of their rights.¹⁶

13 In some states, advance directives made pursuant to a statute may achieve "binding" legal effect (subject, usually, to considerable room for interpretation). See pp. 155-66 *infra*. In such a case, whatever the moral justifications, one may not be legally justified in disregarding the directions.

14 One of the observational studies conducted for the Commission concludes that "on balance the normative patient role in [health care decisionmaking] is one of passive acquiescence." Lidz and Meisel, *supra* note 9, at section 6.

15 A possible exception to this requirement would be an irrevocable grant of decisionmaking power to another, as when Odysseus, wishing both to hear and to resist the lure of the Sirens' call, had himself tied to the mast of his ship and instructed his crew not to release him however much he might entreat them to do so.

16 The critical element is the patient's attitude toward "involvement"

In recognizing that a self-determining person may waive active involvement in each decision, the Commission does not intend to belittle the moral ideal of the free, self-governing person who attempts to make decisions responsibly by applying his or her own values to relevant facts during deliberations about alternative actions. The ideal certainly justifies encouraging patients to play an active part in treatment decisions and argues for structuring medical practices and institutions in ways that facilitate and encourage effective patient participation. Nevertheless, it remains a moral *ideal*—people may strive to meet it but will often fall short of it. The principle of self-determination, the bedrock on which the Commission's concept of shared decisionmaking in health care rests, is best understood as respecting people's right to define and pursue their own view of what is good, which is compatible with people freely giving to others the authority to make particular health care decisions for them.

in the decision, not the mere existence of some "delegation," for all decisions about matters as complex as medical care require a large measure of delegation. Self-determination is not lacking simply because a patient does not insist that the physician review the reasoning and empirical evidence that led up to the physician's recommendation (and its alternatives, if any), including each standardized laboratory test, each anatomical or metabolic finding, and so forth. Rather, patients' decisions are always the end points of a long series of earlier choices made by physicians and others (where many of the steps in action and reasoning are so ingrained that those involved do not even recognize them for the choices they are). What is at issue, then, is merely the *degree* of delegation of decisionmaking authority by the patient to the professional, not the *fact* of delegation. While some patients want to explore every hypothesis, others want to know only the final recommendation; both may be exercising appropriate self-determination.

